

DOA Administrative Letter No. 01-1

To: Area Agency on Aging Directors

Subject: Family Caregiver Support Program

Date: January 30, 2001

Under the legislative authority of Title III, Part E of the Older Americans Act, as amended in 2000 (P.L. 106-501) effective 11/13/00, North Carolina is ready to accept an exciting and significant opportunity to develop a multifaceted support system to respond to the needs of family caregivers. The Division of Aging has received \$2,916,628 to begin this effort. The funds come with several expectations. As the State Unit on Aging, we will:

- work in partnership with Area Agencies on Aging
- move toward full operation of the program as soon as possible
- give priority to older individuals in greatest social and economic need and older individuals caring for children with mental retardation and developmental disabilities
- support caregivers through some combination of: information about services; assistance with access to services; individual counseling, organization of support groups, and caregiving training; respite care; and supplemental services.

Conditions on the funds include the following:

1. The Division may use 5% of the total allotment for State administration.
2. The Division may provide AAAs with up to 10% of the remainder for area plan administration.
3. The funds are to supplement, not supplant, existing services.
4. North Carolina may use up to 10% to provide support services to grandparents and older individuals who are relative caregivers as defined in the law.
5. Not more than 20% of the Federal funding can be dedicated to supplemental services.
6. The Division may use the current Intrastate Funding Formula for allocation of the funds to AAAs (see Attachment #1 for allocation information).
7. The required non-Federal share is 25% (cash or in-kind).

The Role of the Division

The Division of Aging has overall responsibility for assuring the proper expenditure of Title III-E funds and for helping develop a statewide service delivery system that is responsive to family caregivers. The Division intends to implement the program deliberately but expeditiously by keeping administrative tasks simple and by relying on existing resources and previous investments whenever possible. The Division will balance statewide guidance with regional flexibility. *The Division seeks to build adequate capacity within each AAA region to assure that caregivers across the state receive the support intended by this program, and to support the related work of the Institute of Medicine's Task Force on Long Term Care.* The Division's leadership

includes the following *statewide goals* that it hopes to achieve within the first three years of the program:

1. There will be an adequate infrastructure at the AAA and State levels to serve as a platform for future enhancement of support for family caregivers.
2. Every region will have an I&A system that meets the recommendations of the Division's Task Force on I&A.
3. Family caregivers in every county will have access to respite care, counseling and training.
4. AAAs and the Division will know the unmet needs of caregivers for purposes of planning and program development.
5. AAAs and the Division will have contributed significantly to helping the State implement recommendations of the N.C. Institute of Medicine Task Force on Long Term Care, including promotion of the availability of core services and the strengthening of local planning for aging and long term care.

To oversee and support statewide development of the Family Caregiver Support Program, the Division will seek to establish a new position of Family Caregiver Program Specialist who will work very closely with AAAs. While the current budgetary constraints at the state-level may delay hiring someone for this position, it is still the intent of the Division to do this as soon as possible. In the meantime, various Division staff members will share responsibility for supporting work associated with the program's design and implementation. If you have questions about the content of this letter or about next steps, contact Dennis Streets. If you have questions about the funding allocation to your region, contact Gary Cyrus.

The Role of AAAs

The Division believes that Area Agencies on Aging have a prominent role in realizing the potential value of the Family Caregiver Support Program. This appears to be the intent of the Federal law and seems prudent from a practical sense. *The Division supports building the capacity of AAAs so that they can lead in leveraging resources, developing partnerships, identifying and supporting critical needs, expanding successful services, and evaluating the program to guide its future direction.* The Division thinks that this is best accomplished through establishment of a *Family Caregiver Resource Specialist* position in each AAA, who, under the supervision of the AAA director, would:

1. Develop, implement and track the AAA's work plan for family caregiving support, paying special attention to the goal of making such "core services" as *I&A and respite* available and accessible to consumers. This work plan is to be part of Section I of the Area Plan and is to delineate activities among the general categories: information about services; assistance with access to services; individual counseling, organization of support groups, and caregiving training; respite care; and supplemental services. The Family Caregiver Resource Specialist is to consult with at least the following organizations in developing the work plan: (a) regional Alzheimer's Chapter(s), (b) Division of Vocational Rehabilitation's Independent Living Program, (c) Social Services, (d) support groups, (e) Cooperative Extension, (f) Area Mental Health Program, (g) hospice agencies; (h) respite care providers (including ADC/ADHC programs); and (i) lead agencies for local planning on aging. Other recommended

contacts include: Aging Specialist(s) at Area Health Education Centers, community colleges, and area universities; Medicaid CAP; eldercare programs; legal services; and family resource/support centers, which may be involved with kinship care and intergenerational programming. Obviously, the AAA must seek to learn and consider the views of family caregivers in setting priorities, including the relative need for providing support of older grandparents raising grandchildren and of older persons caring for children with mental retardation or other developmental disabilities. In consultation with all of these stakeholders, the Specialist will assess need for expansion of existing services and initiation of new ones. This assessment will include an inventory of the adequacy of resources in the Region, based on "core services" identified in the Long Term Care Plan of the N.C. Institute of Medicine (including I&A and respite), and on the following additional needs of family caregivers: access to assistive technology, support groups, caregiver training, and caregiver counseling. The Specialist will share this assessment and the AAA's work plan with the Home and Community Care Block Grant planning committees. The work plan is to be approved by the AAA's Regional Advisory Council prior to submission to the Division for its review and approval.

2. Lead program and resource development efforts (e.g., networking, grant writing, volunteer recruitment and training). The Specialist will seek working relationships with faith, civic, and employer groups.
3. Provide or arrange for direct services (e.g., public information activities, outreach, I&A, case management, counseling, caregiving training) as determined appropriate based on the needs of caregivers and the resources available in the region. The Specialist will determine how best to target the AAA's caregiver support so that priority is given to older persons in greatest social and economic need and to older individuals caring for children with mental retardation or other developmental disabilities. The Specialist will establish a process for collecting participant contributions, following existing State policy, for service dollars used by the AAA.
4. Establish an adequate system for recordkeeping of clients served, expenditures, and unmet needs. The Specialist will complete quarterly progress reports and assure reporting of data to the Division, using ARMS and/or other State identified means to document the effect of service expenditures. Regions I and N will pilot test use of the "AoA Caregiver Support [Assessment] and Satisfaction Survey" as part of a separate project.
5. Develop and implement area publicity campaign for program. Note that it appears that the U.S. Administration on Aging interprets the "information" service category to include public education and other forms of group information, as well as outreach interventions to identify potential caregivers and encourage their use of existing services and benefits. It will be important for each AAA to develop an effective mechanism to receive input from caregivers on a regular basis.

6. Advocate for the interests of family caregivers. This should include discussions with members of the Senior Tar Heel Legislature and with the Home and Community Care Block Grant Committees.
7. Participate with AAA peers and Division Specialist and other staff members in support of program implementation and evaluation.

Given the level of complexity and importance of these tasks, *the Division encourages each AAA to give serious consideration to the establishment of the position and the hiring of a very qualified individual. The AAA can establish the position using the allocated P&A funds and a portion of the Title III-E services funds. A request for a waiver is necessary in the AAA's use of service funds unless the AAA's direct services are limited to information and assistance and outreach. Any waiver request should be submitted prior to the hiring of the Family Caregiver Resource Specialist and should include an indication of the services to be provided by the AAA.*

Records and Reports

The Division is committed to simplified administration of the program, but it is nonetheless essential that there is a well planned, configured, and understood system for recording and reporting data and other information important to accountability, evaluation and future development. While the Administration on Aging intends to consider revising the National Aging Program Information System to collect data on a permanent basis, we must anticipate the need for information and plan a system that will help us document the value of our work in this area. The Division will work closely with the AAAs in devising and implementing the system. Initially, we expect it to include the following components:

1. Use of ARMS to report expenditures by the five service categories of information; assistance; counseling, support groups, and caregiver training; respite; and supplemental services. (Attachment #4 gives the AOA's example of services that could be reported.)
2. Use of activity logs and contact forms to record and report units and people served by the five service categories, with some explanation of the nature of the service.
3. Use of measurable objectives in the work plan to track progress toward development of partnerships and leveraging of resources.

Staff members at the Division who will lead in developing this system include Ann Cratt, Gary Cyrus, Mark Hensley, Phyllis Stewart, and Harold Berdiansky.

Opportunities for Partnership

Title III-E stipulates that Area Agencies on Aging must coordinate their activities with those of other community agencies and voluntary organizations providing services corresponding to the five service categories outlined in the law (i.e., information, assistance, counseling/support groups/caregiver training, respite, and supplemental services). It is important to identify and build on existing resources and activities, especially where they have been effective. Below is a brief description of several

activities and interests that you might want to consider as you develop the AAA work plan. You would need to negotiate arrangements and costs with the contact people identified for each activity.

Taking Care of You: Powerful Tools for Caregiving. This is a course offered by N.C. Cooperative Extension and the Duke Family Support Program. It was developed in Oregon by a team at Legacy Health Systems in Portland, and has been offered widely in that state, with excellent evaluations. The program was previewed and then recommended by Lisa Gwyther, director of the Duke Family Support Program. The Division of Aging sponsored Edna Ballard of the Duke Program and Luci Bearon of the N.C. Cooperative Extension Service to go to Oregon in January 2000 to have them become Master Trainers.

The course is built on a train-the-trainer model. Master Trainers train Class Leaders (professionals in aging, social work, etc.) and Co-Leaders (laypersons with direct family caregiving experience with elderly relatives), up to 10 pairs at a time, in a course that runs about 2.5 days. The Class Leaders and Co-Leaders then offer the class to 10-15 caregivers in their communities over 6 sessions (about 2.5 hours in length), usually one session per week for 6 weeks. The curriculum for the course is fully scripted and focuses on self-care for the caregiver, not how to take care of the patient, although surely the patient will benefit by having a less stressed caregiver. It is designed to provide family caregivers with the tools to increase their self-care and their ability and confidence to handle difficult situations, emotions and decisions. The six sessions cover: (1) Taking Care of You; (2) Identifying and Reducing Personal Stress; (3) Communicating Feelings, Needs and Concerns; (4) Communicating in Challenging Situations; (5) Learning from our Emotions; and (6) Mastering Caregiving Decisions.

Because this is a packaged program governed by Legacy, only Master Trainers can train Class Leaders and Co-Leaders and the training materials cannot be altered. Also, local programs require a pair of Class Leaders and Co-Leaders willing to do the six-week program together, so people must be recruited in pairs to come to our training with the idea they will return home and work together. If interested, you can contact Dr. Luci Bearon about program costs and arrangements. Contact her at: N.C. Cooperative Extension Service, Box 7605 NC State University, Raleigh, NC 27695-7605, lbearon@email.com, 919-515-9146.

Grandparent Caregivers. The N.C. Cooperative Extension Service is interested in establishing an education, training, outreach, and public information program focused on supporting North Carolina's grandparent caregivers. This could include: (1) producing a curriculum for use in training Extension agents and community volunteers who would then provide information and educational services to grandparent caregivers; (2) developing a public awareness campaign about the issues facing grandparents raising grandchildren; (3) training personnel in the aging network and other service professionals to work with and address specific needs of grandparent caregivers; and (4) providing technical assistance to county Extension staff so that they can develop coalitions, find funding, and develop programs to meet local needs. For further information, contact Dr. Luci Bearon at: N.C. Cooperative Extension Service, Box 7605 NC State University, Raleigh, NC 27695-7605, lbearon@email.com, 919-515-9146.

Respite Care for Caregivers of People with Alzheimer's/Dementia. The N.C. Alzheimer's Association is interested in further developing an approach they have begun to expand awareness, availability, and utilization of respite care for families caring for a person with Alzheimer's disease or a related dementia. They point out that for many Alzheimer families, respite is the basic service that enables them to keep their loved one at home. The Association proposes a demonstration project using a voucher-type system for respite care. To be successful, the Association believes that there must be a "lead agency" to administer the program locally and a comprehensive network of caregiver support services available in the county, to include: information and assistance; caregiver support groups; caregiver education and training; agencies that provide in-home sitter, homemaker, and personal care services; adult day care; and facilities willing to accept patients on a short-term basis. The role of the lead agency would include: advertising the "respite care vouchers" (suggested to be \$500); providing information and case assistance to family members; processing application for respite and providing approved voucher to caregiver; reimbursing respite providers up to approved amount; and providing follow-up assistance to the family. For further information, contact Barbara D. Hinshaw, at the Western North Carolina Chapter of the Alzheimer's Association, 3 Louisiana Avenue Asheville, NC 28806-3419; 828-254-7363, or 1-800-522-2451; alzwncc@brinet.com.

Community Dialogues and Collaborative Real-time Planning. The Center for Aging Research and Educational Services (CARES), at the Jordan Institute for Families, School of Social Work, University of North Carolina at Chapel Hill offers training and consultation on community dialogues and collaborative real-time planning to assist AAAs and their communities organize planning efforts that capture the voices of community stakeholders, especially caregivers and their families. This process brings together between 50 and 200 people for a two-day event that leads to an action plan based on identified outcomes. The process has been successfully used both within the state and nationally to identify measurable outcomes that respond to community wishes; foster collaboration and inclusion, as well as responsibility for change, among citizens and community organizations; develop a specific performance plan with measurable goals and action steps; and effect rapid change. In addition to facilitating the process, CARES offers pre- and post-planning technical assistance. The Cape Fear AAA (Region O) used this process for its elder rights community planning project (ROAR). For further information, contact Linda Rahija at: CARES, UNC-CH School of Social Work, 301 Pittsboro Street CB #3550 Chapel Hill, NC 27599-3550 919-962-5163, lrrahija@email.unc.edu.

Duke Family Support Program. Duke University's Family Support Program is nationally recognized for providing assistance to caregivers of the chronically ill and demented and has served a major resource for training healthcare professionals and the Alzheimer's Association chapters who maintain local support groups. For the purpose of the new Family Caregiver Support initiative, the Duke program is particularly interested in serving as a resource in at least four areas: (1) development and implementation of employee assistance programs for working caregivers [the Duke program is providing eldercare services for Duke University employees and their families]; (2) adaptation of a

"family consultation model" proven successful in California's Family Resource Centers [the model helps families through their periods of critical decision-making]; (3) identification and coordination of strategies to help caregivers with end-of-life issues [the Duke Family Program works closely with Duke Divinity School's End-of-Life Institute, which also uses faculty at UNC-Chapel Hill and N.C. Central University]; and (4) consultation and program development on all matters concerning Alzheimer's disease and other dementias [e.g., adaptation of Georgia's model of a mobile day services program for respite care]. For further information about any of these areas, contact Lisa Gwyther, director of Duke Family Support Program, at 1-800-672-4213, or 919-660-7510; lpg@geri.duke.edu.

Advance Care Planning. The Carolinas Center for Hospice and End of Life Care is promoting efforts to build a network of local trainers and community facilitators to support advance care planning. According to the Center, only half of the people who die in the Carolinas have a Durable Power of Attorney for Health Care or a Living Will. Difficulties occur when caregivers do not know a person's choices for end-of-life medical care. Many middle-age adults report difficulty talking with their elderly parents about end-of-life care. The Center is currently sponsoring Advance Care Planning Instructor's Certification Training. For further information about the work of the Center, contact Gwynn Sullivan, director of the Center's NC Community Outreach, P.O. Box 4449, Cary, NC 27519-4449; 919-677-4117.

Best Practices in North Carolina and Other States

In our November survey of AAAs and Division staff members, people wanted to know more about what is already working well in North Carolina to support family caregivers and about other states' model activities that might be adapted for use here. While clearly this will have to be done on an ongoing basis, we do want to share with you what we learned from our efforts thus far. Attachment #3 gives you what information was provided to our request for "best practices" at our Special Forum on Caregiving in December (Wanted! Survey Results). We have also prepared a summary of "Ideas for Family Caregiver Support Projects" from our review of the literature. For further information about what other states are doing, contact Yoko Crume at the Division.

Timeline

Developmental Period (January 2001 - June 2002)

1. State Division and AAAs hire Family Caregiver Resource Specialists, and establish and implement initial work plans that may include contracts with other entities.
2. State Division establishes standards and mechanisms designed to assure the quality of services provided under this program.
3. State Division and AAAs design and implement means for recording and reporting information to monitor program administration and compliance, and to evaluate the program's effectiveness.

We envision the following dates for initial implementation of the program by AAAs:

February 16, 2001--Complete and return Attachment #2, **Area Agency Statement of Intent and Interest**

March 30, 2001--Hire Family Caregiver Resource Specialist

May 31, 2001--Submit to the Division the AAA Work Plan for Family Caregiver Support initiative, which reflects input from appropriate groups and delineates activities among the categories of services authorized by law: information about services; assistance with access to services; individual counseling, organization of support groups, and caregiver training; respite care; and supplemental services. The Division will provide a basic format for documenting the work plan.

June 30, 2001--Division reviews/approves AAA work plans and notifies AAAs of acceptance.

Definitions and Clarifications

SEC. 372. Definitions.

 In this subpart (Title III-E)

Family Caregiver- The term "family caregiver" means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual.

Grandparent or Older Individual Who Is a Relative Caregiver- The term "grandparent or older individual who is a relative caregiver" means a grandparent or stepgrandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and--(A) lives with the child; (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and (C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally. "Child" is defined as "not more than 18 years of age."

Service Categories

From information provided by the Administration on Aging, the Division is using the following as a starting point for characterizing the five service categories identified in the law. The Division will work closely with AAAs in refining the scope of these categories. Please indicate on Attachment #2 if you wish to participate in this work. Lead staff members at the Division will include: Yoko Crume, Steve Freedman, Heather Burkhardt, and Marian Sigmon.

Information: Considered more of a group service (e.g., public education, participation at health fairs).

Assistance: Considered more of an individual, one-on-one contact to assist caregivers in gaining access to services (e.g., information and assistance, case management).

Counseling/Support Groups/Training: Provision of advice, guidance, and instruction to caregivers on an individual or group basis, to assist caregivers in making decisions and solving problems relating to their caregiving roles.

Respite: Temporary, substitute supports or living arrangements to provide a brief period of relief to caregivers on an intermittent, occasional or emergency basis.

Supplemental Services: States are given the authority to determine the scope of what is allowed under "supplemental services." The one federal stipulation is that these services are to be used on a "limited" basis to complement the care provided by caregivers, with no more than 20 percent of the federal funding dedicated to them. The North Carolina Division of Aging will allow considerable flexibility to AAAs in defining "supplemental services," except to emphasize that the focus must be on supporting the needs of caregivers. The Division will require the AAA to advance notice of any "supplemental service" that will be funded so that the Division may assure its appropriateness and track the use of this category of service. Examples of supplemental services might include: home safety audits and home modifications; assistive technologies; emergency alarm response systems; and incontinent and other caregiving supplies. Some consideration may be given to using the funds for such purposes as providing a home-delivered meal or medical transportation, but this would have to be on a temporary basis and only if it supports the needs of caregivers.

Area Agency Statement of Intent and Interest

The Division of Aging requests that each Area Agency on Aging complete and return this form by Friday, February 16, 2001, if at all possible. Fax, mail, or email it to Dennis Streets at the Division. We will use this information to continue our state-level planning. We realize that this may be an unofficial response from your agency because you may not have had time to brief your Council of Governments Board, Regional Advisory Council or others.

1. Is it your intent to establish a Family Caregiver Resource Specialist position at the AAA?

☐ Yes, on a full-time basis

☐ Yes, on a part-time basis or with part-time responsibilities

☐ No

Explanation, if needed:

2. Are you interested in supporting with your region's Title III-E allocation any of the initiatives described in the Administrative Letter:

Taking Care of You: Powerful Tools for Caregiving

☐ Yes

☐ No

☐ Not sure. Would like to know more about the initiative.

Grandparent Caregivers

☐ Yes

☐ No

☐ Not sure. Would like to know more about the initiative.

Respite Care for Caregivers of People with Alzheimer's/Dementia

☐ Yes

☐ No

☐ Not sure. Would like to know more about the initiative.

Community Dialogues and Collaborative Real-time Planning

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☐ Yes

☐ No

☐ Not sure. Would like to know more about the initiative

Consultation from Duke Family Support Program

- ☐ Yes
☐ No
☐ Not sure. Would like to know more about the initiative.

Advance Care Planning

- ☐ Yes
☐ No
☐ Not sure. Would like to know more about the initiative.

Explanation, if needed:

3. When the AAAs next meet in Raleigh on February 28 and March 1, the Division would like to hold a work session on this program. Please check below the areas about which you are especially interested in working:

- ☐ Design system for recording and reporting data and other information
☐ Plan for statewide publicity about the program
☐ Design job expectations for Family Caregiver Resource Specialist at AAA
☐ Develop approach for using this opportunity to influence local planning for long term care
☐ Define what is meant by the service categories, and especially "supplemental services"
☐ Develop format for AAA work plan
☐ Discuss process for AAA collection of participant contributions for any direct services it provides

Other comments and questions you may have:

Region_____

Signature of AAA Director

Date